Paralyzed Veterans of America



New England Chapter

THE NEWSLETTER OF THE NEW ENGLAND CHAPTER PARALYZED VETERANS OF AMERICA

A Busy Six Months Ahead

by Mark Murphy, Executive Director NEPVA

was recently looking over our Chapter events and meetings schedule for the rest of this calendar year, and we have an action packed 6 months ahead. For my article this month I would like to outline many of these happenings as they will hopefully positively impact our members and the Chapter in general. Before I get to that, we have had a couple recent events and projects that I want to highlight. You may be aware that PVA National mandates that each Chapter has an updated and current Policies and Procedures Manual. The last time ours was officially updated and approved was in February of 2021, so it is time to make some adjustments. Over the past couple of months, I have been working closely with a team from National to update ours, and it has been a huge project to undertake as the current document is over 75 pages long. Much of it is very repetitive and unnecessary, so we have worked to cut the superfluous fluff out. We hope to put this up for a Board vote at their meeting this month.

On March 29th I was honored to be invited to attend The Boston Home in Dorchester's open house, which included a special presentation from the Spaulding Adaptive Sports Center. Kristen McCone Gordon and Board Treasurer Chuck Houle and his wife Eileen also attended, and we



were delighted to be warmly welcomed, meet several staff members and residents, and get a tour of their beautiful facility. The Boston Home is an amazing place, and they do incredible work. We look forward to perhaps partnering with them on things in the future.

Now, here are some major events and meetings for the rest of the year. This list is of course not exhaustive, but is rather a snapshot of many important things we have on the horizon:

- The 78th Annual PVA Convention in Minneapolis from May 13-19.
- The 2024 Advocacy/Legislation Seminar in Washington D.C. from June 10-14.
- National Veterans Wheelchair Games in New Orleans from July 25-30.
- Our 4th Annual Chapter Golf Tournament at the South Shore Country Club in Hingham on August 19.
- Annual membership gathering at the ITAM Post in Marlborough on September 8.
- "Ad/Leg 2.0" in September/October (specific dates still to be determined)
- 2024 PVA Fall Board of Directors Meeting in Orlando in October (specific dates still to be determined)

continued on page 3

Join Us Outside this Summer

VA Summer Sports Clinic, July 22-26, Rhode Island

National Veterans Wheelchair Games, July 25-30, New Orleans

NEPVA Chapter Golf Tournament August 19, Hingham, MA

A MEMBER CHAPTER OF THE PARALYZED VETERANS OF AMERICA – CHARTERED BY THE CONGRESS OF THE UNITED STATES

Cord Word



SAVE THE DATE

NEPVA Chapter Golf Tournament August 19 South Shore Country Club Hingham, MA

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Cord Word

April 2024

Executive Director's Report continued from page 1

As you can see, it will be a busy 6 months ahead, and I am sure each of these activities will show the vibrancy and life of our Chapter while forging new memories together. All these events also take an incredible amount of time and effort to plan, so a big pre-thank you to our staff, Board,

volunteers, and our friends at PVA National for all their

In closing, I would like to officially share with you that as of April 5th Peter Demarkis has moved on from his position as Senior Benefits Advocate/NSO for PVA. I know that Sincerely, many people in our community have worked with Pete over the past several years, so I wanted to be sure to inform you of this. I have no news of a replacement for Pete, but when I do, I will let you know. In the meantime, Michael

Dear NEPVA Members,

hard work and dedication.

irst a brief introduction: in 1969 I joined the WAC d time when many of my male classmates were being drafted into the military during the Vietnam Conflict. My PDS was Ft. Benning, GA, where I became service-connected disabled. I worked as a dental specialist.

I hope all our NEPVA female veterans to benefit other memconsider joining us on April 30th at noon bers. Anita Bloom, author of, "Beyond Dancing: A Veteran's Struggle," was a pioneer. to learn more about what PVA, and the It is with her spirit and dedicated efforts that I offer my NEPVA Chapter, can offer you! help.

I hope all our NEPVA female veterans consider joining us on April 30th at noon to learn more about what PVA, and Fast forward to 1999, when I was diagnosed with multiple the NEPVA Chapter, can offer you! sclerosis. In 2000, I became a member of PVA & I enjoyed the "PN" magazine & the NEPVA newsletter, "Cord Word." Being born & raised in coastal mid-Maine, not Sincerely, knowing many women veterans, I jumped at the chance to Bernice Bartlett DeBlois travel to attend a WVER (Women Veterans Empowerment NEPVA Board Member Retreat.) Living a rather isolated life can get boring, & PVA changed that! The PVA staff at the WVER kept us busily

April 2024

By Mark Murphy Executive Director NEPVA

Snape and Zachary Nuetzel will continue their NSO services as usual. If you have any questions, please feel free to reach out to me directly.

> I hope you enjoy these next weeks of Spring and the promise of warmer weather!



Mark Murphy **Executive Director**

s,	interested in seminars &
	activities such as yoga, art,
1	& togetherness.

To show my appreciation to PVA, I am looking forward to volunteering my time



April 2024





For more than 75 years, PARALYZED VETERANS OF

AMERICA—the only congressionally chartered veterans service organization dedicated solely for the benefit and representation of veterans with spinal cord injury or diseases (SCI/D), like MS and ALS—has led the fight for accessibility and provided a full circle of support from the point of injury or diagnosis to all of life's milestones. With offices inside every Department of Veterans Affairs (VA) SCI/D center

across the U.S., PVA is unmatched. Staffed with licensed architects, medical professionals, legal experts, and leaders in research and education, PVA fights to help veterans with SCI/D receive the benefits they earned, the specialized health care they deserve, the accessible homes and vehicles they need, and the meaningful careers they want. PVA also advocates for disabled veterans with the greatest support needs to have equitable access to the same opportunities and freedoms available to all Americans.

To review PVA's policy priorities in depth, please visit PVA.org.

Protect Access to VA's Specialized Health Care Services

VA's health care system must receive sufficient funding in order to continue providing the specialty care needed by veterans with SCI/D. Without adequate funding, VA will not be able to properly care for veterans, hire and retain health care professionals and support workers, and maintain and expand VA's medical infrastructure. PVA advocates for proper funding for VA's SCI/D system of care through the Independent Budget—a partnership with DAV, PVA, and VFW. Critical reforms are also needed so VA can adequately meet veterans' health care needs.



Staffing

VA must effectively use the pay and workforce provisions approved in Public Law 117-103 (RAISE Act provisions) and the PACT Act (Public Law 117-168) to recruit and retain necessary health care professionals, particularly those needed for VA's SCI/D system of care. VA must also increase retention incentives and reform its hiring processes, including working with Congress to make needed reforms. Congress must also take additional action to boost pay caps for other providers not included in the RAISE Act provisions and PACT Act.



Infrastructure

VA's infrastructure processes need to be reformed and staffing increased to allow the department to effectively use needed funding. VA also must develop a nationwide infrastructure plan to better address the SCI/D system's unique care delivery model.

VA's services span the spectrum from facility-based care to home and community-based services. Increased availability of long-term services and supports is crucial to the ongoing health of paralyzed veterans, as well as ensuring all veterans are able to receive the care they need throughout their lives in the setting of their choice.



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Facility-Based Long-Term Care

VA must adequately assess the number of veterans with SCI/D who need facility-based specialty long-term care and implement policies that will increase beds and prioritize related infrastructure projects.

Home and Community-Based Services and Caregiver Supports

Congress and VA must increase access to home and community based-services, including expanding programs like Veteran-Directed Care and modernizing VA's Bowel and Bladder program for family caregivers. Congress and VA must also prioritize efforts to increase the direct care workforce that provides the services and supports veterans with SCI/D require to live in their communities. In addition, veterans must be authorized to receive a sufficient number of hours of support each week to ensure their daily needs are met.

VA must reform the Program of Comprehensive Assistance for Family Caregivers (PCAFC). Restrictive eligibility criteria have kept some paralyzed veterans from being found eligible for this program. For those veterans who are not eligible for the PCAFC, VA should provide them with more information about other programs available to help them, including the general caregiver program. VA must also ensure that veterans found eligible for the program are assigned the appropriate tier for their caregiving needs.

NEPVA Members invited to participate in a documentary on the 2024 election

The National Disability Rights Network, a leading national disability rights organization, is working on a documentary short that will tell the stories of voters with disabilities in the lead up to the 2024 presidential election. We will be doing interviews in Maryland, Massachusetts, New Hampshire, South Carolina, Virginia and the District of Columbia. We want to capture the issues that motivate voters with disabilities and paint a rich picture of their lives, because our community, despite being over 25% of the American population it's often ignored by politicians.

2024 POLICY PRIORITIES



Expand Access to VA Long-Term Services and Supports

We want to capture the issues that motivate voters with disabilities and paint a rich picture of their lives...

We are seeking to get a look at the home life and day-to-day of voters with disabilities so we can connect the political issues that matter to their daily life. Interviews would take approximately two to three hours. We want to conduct the

Government Relations Report

Dear NEPVA Members,

Kristen McCone Gordon Director of Government and Community Affairs

April 2024

T'm pleased to share the following updates on the work the Chapter is doing in some of Lour key program areas. We have several offerings in April, including a zoom for our MS members and the kick-off of our NEPVA women veterans' initiative. I hope that you consider joining us and learning more about what these programs can offer you. We are gearing up for a busy (and fun!) spring and summer. I look forward to seeing everyone in the warmer weather.

With gratitude for your service, Kristen McCone Gordon

NEPVA Women Veterans Initiative Kick-off Zoom on April 30th

omen Veterans make up 1.8 million of the U.S. population, of which roughly 10 percent are disabled and enrolled with the Department of Veterans Affairs. They are the fastest growing Veteran population, yet many of these women reportedly feel forgotten and pushed aside while trying to navigate a system that wasn't designed to address their unique healthcare needs.

... we are here to listen to and serve our women veterans.

At the New England Chapter, we are here to listen to and serve our women veterans. Please join us for our inaugural NEPVA Women's Veteran Zoom on April 30th at noon to learn more about what PVA can offer you. All women veterans are invited and encouraged to attend!

Zoom link:

https://us06web.zoom.us/j/87285976995?pwd=uLrxTK nXvnIwT0JmhHfCfBlVa2pY0j.1





Preparations underway for the Advocacy Legislative Seminar in Washington, D.C.

Our advocacy team is gearing up for another successful AD/LEG in Washington, D.C. in early June. This year I will be joined by Brad and Kathy Carlson, Gary Jezierski, Mark Murphy, and Chapter Volunteer Denise Pease.

Please be sure to review PVA's 2024 Legislative Priorities (beginning on page 3) and stay tuned to hear which congressional offices we will be meeting with!

2024 PVA Priorities

Protect Access to VA's Specialized Health Care Services

Expand Access to VA Long-Term Services and Supports and their Survivors

Improve VA Benefits and Health Care Services for Paralyzed Veterans and their Survivors

Protect the Civil Rights of People with Disabilities

Improve Access to Social Security Benefits

Increase Employment Prospects for Veterans with Disabilities

Cord Word

NEPVA's BUILDING COMMUNITY Veterans with MS Program INFORMATION SHARING Upcoming zoom for the NEPVA with MS program on April 16th

Informational Zoom: Ask a Social Worker!

ll NEPVA members with MS and their caregivers are invited to an informational zoom on April 16th at 5:30 p.m. with VA social workers Michelle Turcotte-Smail and Tina Birdsall. Co-hosted by NEPVA Director Chuck Houle, the zoom will include a brief presentation on benefits available to veterans with MS followed by an informational Q&A session.

Presenters:

Chuck Houle: Member of the New England Chapter Board of Directors and Chapter MS lead to National PVA.

Michelle Turcotte-Smail, LICSW:

Spinal Cord Injuries and Disorders Clinic and Polytrauma Clinic Social Work Coordinator at the White River Junction VA Medical Center. Michelle has worked for Veterans Health Administration for 14 years in the Spinal Cord Injury/Disorders Clinic, Polytrauma Clinic, Primary Care, and Geriatrics.

Cristina Birdsall, LSCW:

Rreceived her Bachelor's Degree in Psychology from University of Connecticut and her Master's Degree in Social Work from Southern Connecticut State University. She began her social work career at the West Haven VA in 2012 on the inpatient hospital units before transitioning to the Spinal Cord Coordinator position in 2016. Tina took over the role as ALS Coordinator in 2020.

Please contact Kristen McCone Gordon at kristen@ pvanewengland.org with any questions on this event or NEPVA Veterans with MS program.

Join Zoom Meeting: https://us06web.zoom.us/j/81131798 705?pwd=i0xwqY7QdgScea8gDChWHt3jnK4Mkj.1

NEPVA VISITS THE BOSTON HOME



long with Chuck and Eileen Houle and Executive Director Mark Murphy, I attended The Boston Home's Open House featuring Spaulding Adaptive Sports Centers on March 29th. The Boston Home is a well-established community for adults with MS and other advanced neurological disorders and offers residential care as well as wellness programs for those in the larger community.

We watched an interesting demonstration from the Spaulding Adaptive Sports Centers team that described the opportunities and programs they offer and checked out their state-of-the-art equipment. We were also given a private tour and our entire group was really impressed by the facility, recreational opportunities, and particularly their wheelchair repair room. Please be on the lookout for more information on the Boston Home in future cordword editions, and in the meantime, check out their website at the bostonhome.org.

I'd like to give a special thank-you to Chuck and Eileen Houle for traveling from Vermont for this event. The NEPVA Veterans with MS Program is very fortunate to have Chuck as he is constantly looking for opportunities and information to disseminate to our membership. Many thanks for making the trek down from Vermont, Chuck and Eileen!

Meeting ID: 811 3179 8705

Passcode: 124060

2024 POLICY PRIORITIES

April 2024



NEPVA WOMEN'S VETERAN NETWORK JOIN US FOR OUR INAUGURAL ZOOM APRIL 30TH AT NOON

Women Veterans make up 1.8 million of the U.S. population, of which roughly 10 percent are disabled and enrolled with the Department of Veterans Affairs. They are the fastest growing Veteran population, yet many of these women often feel forgotten and pushed aside while trying to navigate a system that wasn't designed to address their unique healthcare needs.

PVA's ties to women Veterans date back to its first meeting in 1946 with the arrival of its first female Veteran member, Anita Bloom (affectionately known as "Nita"), who fought to ensure women Veterans' healthcare needs were properly met. PVA continues Nita's legacy to this day as part of its Women Veterans Initiative. From the development of its Anita Bloom Committee and creation of its Women Veterans Empowerment Retreat to its advocacy efforts and informative webinars, PVA serves as the nation's leader in securing safe, equal, and accessible health and wellness services that are at least equal to what they had prior to joining the service and suffering a disability.

The New England Chapter of Paralyzed Veterans of America is committed to listening to and serving our women veterans! Please join us for our inaugural NEPVA Women's Veteran Zoom on April 30th at noon to learn more about what PVA can offer you. All women veterans are invited and encouraged to attend!

Zoom link: <u>https://us06web.zoom.us/j/87285976995?pwd=uLrxTKnXvnIwT0JmhHfCfBIVa2pY0j.1</u>

Please contact Kristen McCone Gordon, NEPVA's Director of Government and Community Affairs, with any questions! Kristen can be reached at kristen@pvanewengland.org



— www.pvanewengland.org



Improve VA Benefits and Health Care Services for Paralyzed Veterans and their Survivors



Veterans and Survivor Benefits

Congress must increase VA Special Monthly Compensation/Aid and Attendance benefits for catastrophically disabled veterans to offset increased costs for home care and other needed supports.

Congress must continue to improve access to services and benefits for veterans who have experienced military sexual trauma.

Congress must pass legislation ending forfeiture of military retirement pay to receive VA disability compensation.

Congress must increase the rate of Dependency and Indemnity Compensation (DIC) for surviving dependents and lower the eligibility threshold. Congress must also ensure survivors of ALS veterans have access to enhanced DIC benefits.



Transportation Programs and Supports

Congress must authorize veterans who have nonservice-connected catastrophic disabilities to receive adaptive equipment from VA to drive their vehicles. VA and Congress must also provide improved transportation services and supports that help veterans access needed health care, including increasing the beneficiary travel reimbursement rate and reforming the reimbursement process.



Life Insurance Benefits

Congress must reform VALife to allow premium waivers for catastrophically disabled veterans and ensure ALS veterans' survivors receive these critical benefits.



Home Modification Grants

Congress must raise the rate of funding available through VA's Home Improvements and Structural Alterations grant program to allow eligible veterans to access needed housing modifications due to their disabilities.



Health Care and Benefits for Women Veterans

VA must consider the unique needs of women veterans with SCI/D when delivering and developing services and benefits, including those that are gender specific.



Assisted Reproductive Technologies

Congress must repeal VA's ban on IVF and authorize VA to provide assisted reproductive technology, including IVF, surrogacy, and gamete donation at VA for any veterans enrolled in VA health care.

New England Chapter

Service Officers Report

ith earthquakes and solar eclipses, it has been an interesting start to spring. I hope everyone is safe and enjoying the warmer weather that Springtime brings. This article is a continuation of the recent series of articles between NSO Michael Snape and I on survivor benefits.

As previously discussed, many of our veterans will often ask us what their families will receive upon their passing. In this article, I wanted to discuss a recent change that may impact some of our veterans and their survivors. Since we have discussed Dependency Indemnity Compensation (DIC), I wanted to bring attention to the recent change in its relationship to the Survivor Benefit Plan (SBP) This article will discuss the Survivor Benefit Plan, the old relationship to Dependency Indemnity Compensation, recent changes, and some questions that may arise.

The Survivor Benefit Plan may have an impact on our veterans who retired from the military. SBP is a benefit that is available to opt into while retiring. In essence, SBP works similarly to a life insurance policy. The retiree pays premiums that come out of their gross retirement pay. This is beneficial because, unlike compensation, military retirement pay is taxable. The amount the retiree pays into the Survivor Benefit Plan is excluded from their taxable income. Upon the death of the retiree, the survivor, or annuitant, receives an inflation adjusted percentage of the military retirement pay. A major benefit of SBP, when compared to the common life insurance policy, is that it continues for the life of the survivor and includes cost of living and inflation increases over time. If you are a veteran who pays into the SBP, or are in the process of retiring and considering opting into the benefit, the next section of this article will discuss the historical relationship to Dependency Indemnity Compensation.

Historically, eligible survivors of both SBP and DIC were subject to a reduction in their annuity. Previously, survivors who were in receipt of DIC were subject to a dollar to dollar reduction of their SBP. This would often cause their annuity to be partially or sometimes fully offset by DIC. This was known as the SBP-DIC offset. However, The National Defense Authorization Act of Fiscal Year 2020 made a huge change in the relationship between the SBP-DIC offset.

by Michael Snape,

Senior National Service Officer

The National Defense Authorization Act of Fiscal Year 2020

implemented a phase out of the SBP-DIC offset. This phase out

since January 1st, 2023. The new relationship between SBP and

mean for the eligible survivors? This means that now, upon the

death of a retiree who opted into SBP and their death meets the

requirements for DIC, the survivor and/ or survivors will now be

eligible to receive their full Dependency Indemnity Compensation

concurrent with their Survivor Benefit Plan. A common question

Unfortunately, if the retiree did not opt in at the time of retire-

ment, they are not eligible to opt in at a later date. NOTE: Some exceptions may apply. SBP does occasionally allow for an open

enrollment period. These would require a payment of past premi-

ums due. For example, if a veteran retired in 2006 and they allow

for opting-in, the veteran would have to pay the premiums going

back to their date of retirement. These would be payable through

What does this mean for our retirees? If, upon retirement, you opt

into SBP, and you pass away due to a service connected disability,

or you are rated permanent and totally disabled for 10 years, or

rated permanently and totally disabled for 5 years immediately

be able to receive their DIC payments on top of their SBP pay-

to you, and you have additional questions about your eligibility,

after discharge, and thus eligible for DIC, your survivor(s) will now

ments. If you are a retiree or believe that these benefits may apply

please feel free to contact your local PVA National Service Officer.

eligibility.

Respectfully,

Zachary T. Nuetzel

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National Service Officer

Paralyzed Veterans of America

that retirees may pose with this change is: Can I now opt into SBP?

occurred over the course of a few years and has been in full effect

DIC is that, there is now no offset between them. What does this

Cord Word

documentary continued on page 5

interview and film footage to complement it. For example: navigating to work, arranging paratransit, going over how much their healthcare costs or showing any durable medical equipment they use, explaining how a home health aide would enable them to experience greater independence.

The goal of this project is to highlight the biggest minority group that often gets ignored by the candidates of all parties. The project is strictly nonpartisan. We are seeking to ensure we have a diverse range of perspectives included in terms

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of the issues that matter and the life experience those voters come with.

We are looking to speak to first time and longtime voters, we want to interview those fresh out of school (and even graduating seniors) as well as people who have spent a long time in the workforce or even found themselves excluded from the workforce. We want to speak to voters with disabilities of all stripes and capture the diversity of our community.

If you are interested, please contact us at storytelling@ndrn.org. We look forward to working with you to help politicians understand that our community cannot be ignored any longer. Please note that, following documentary film making best practices, we are unable to pay interview participants.

TOGAS, VARO, I VA CENTER

MANHATTAN

Zachary T. Nuetzel, National Service Officer Paralyzed Veterans of America 201 Varick St., Room 4W59.50 New York, NY 10014 phone: (202) 416-1075 zacharyn@pva.org Serving New York, New Jersey and Connecticut

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2024 POLICY PRIORITIES



Protect the Civil Rights of People with Disabilities

Protecting the civil rights of people with disabilities is important to ensuring their ability to access the opportunities and freedoms available to all Americans to allow them to live, work, travel, and fully participate in society.



Improve Access to Air Travel

Congress must make systemic changes in the next FAA Reauthorization to improve air travel for people with disabilities, particularly wheelchairs users, by reforming the Air Carrier Access Act to add standards for aircraft accessibility and improve enforcement of the law. Congress must also improve paralyzed veterans' access to programs that facilitate the security screening process.



Increase Disability Access

Congress must enhance tax incentives to help businesses comply with their obligations under the Americans with Disabilities Act (ADA). Also, the Department of Justice (DOJ) must investigate more individual ADA complaints and publicly report information on filed and adjudicated complaints. DOJ must also issue long-overdue regulations related to hotel bed height and accessible medical equipment standards.

Industries creating new models and forms of transportation, including electric and autonomous vehicles, must ensure disability access as a matter of equity. Existing transportation providers must also increase accessible features to ensure greater access for people with disabilities.

Improve Access to Social Security Benefits

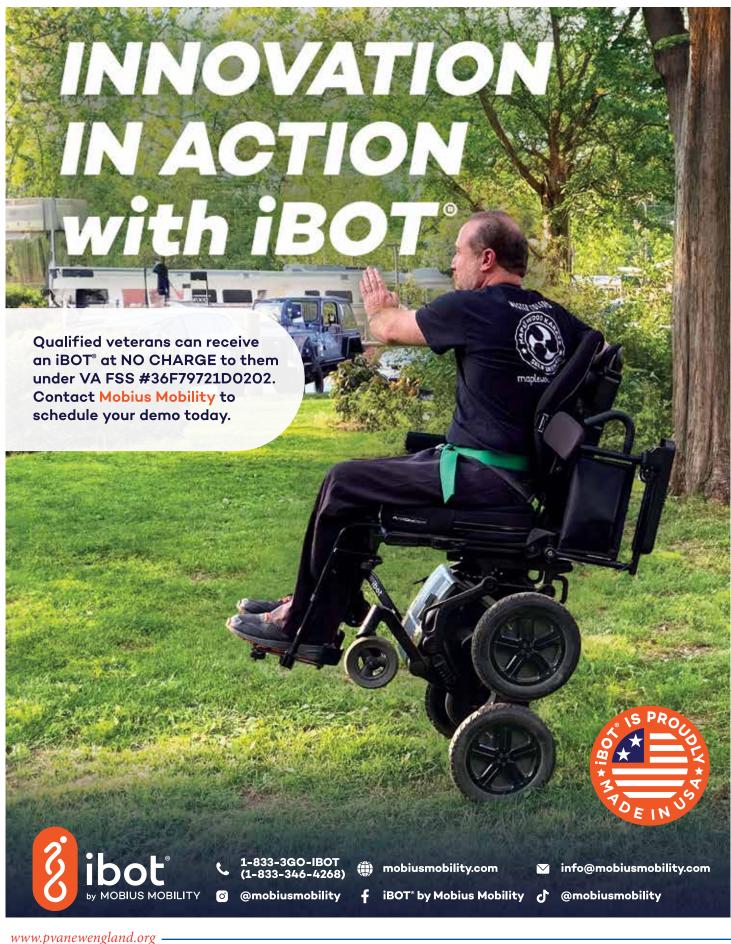


Congress must end the five-month wait for Social Security disability insurance benefits to ensure people with disabilities have financial support when they most need it. Congress must also ensure that caregivers who are out of the workforce due to caregiving responsibilities are able to receive credit under Social Security.

Increase Employment Prospects for Veterans with Disabilities



Congress must increase access to employment opportunities for veterans with significant disabilities through tax incentives for employers and improvements to supports provided to veterans through the state workforce system. VA's Veteran Readiness and Employment program must ensure veterans with catastrophic disabilities are able to fully access the services that allow them to return to work.







April 2024



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Office Hours: Monday-Friday 9:00am-4:30pm



New England Chapter

Major Steven Roy Andrew's Fishing Outreach

May 7, Candlewood Lake Danbury, CT

September 17, Lake Congamond, Southwick, MA

Join Us at Our Upcoming Events

additional dates to be announced soon.

VA Field Day June 22, Brockton VA

VA Summer Sports Clinic, July 22-26, Rhode Island

National Veterans Wheelchair Games, July 25-30, New Orleans

NEPVA Chapter Golf Tournament August 19, Hingham, MA

Visit Us at pvanewengland.org for all the latest event info